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ABSTRACT

This training guide presents a model for optimum delivery of the primary duties, tasks, and steps required in the comprehensive case management of adolescents with chronic disease. Using a team approach to coordinated health care, the guide involves the patient and family as key members of the care team along with the physician, nurse, dietitian, psychologist, social worker, and exercise physiologists. The guide offers training to provide medical, educational, and psychosocial support to help adolescents achieve optimal health and successful transitions to adult care. Selected by a team of pediatric endocrinologists in a Develop A CurriculUM (DACUM) workshop, the major duties focus on diabetes, but the resulting profile provides a general model for chronic illness. Results from a task verification survey instrument sent to 100 randomly selected members of the American Diabetes Association indicate the professionals' perceived importance of tasks presented relative to training outcomes. Tasks teach how to: (1) maintain contact; (2) provide individualized care; (3) provide education; (4) improve patient's health; (5) ensure appropriate equipment; (6) provide psychological support; (7) address economic and social needs; (8) foster community awareness; (9) maintain professionalism; and (10) keep patient records. Each task is subdivided into competencies. For each competency, performance objectives, person primarily responsible, and steps to achieve the objective are given. Nine references and a separate competency profile are included. (NLA)

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CASE MANAGEMENT OF ADOLESCENTS WITH CHRONIC DISEASE

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CASE MANAGEMENT OF ADOLESCENTS WITH CHRONIC DISEASE

by

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FOREWORD

The Maternal and Child Health research priority regarding the validation of current health care practices attests to the need to continually update, review, educate and train nurse educators, physicians, and other personnel who are responsible for health care delivery. The case management of women and children with special health needs requires a unique combination of knowledge and skills. Finding the most comprehensive, efficient, and effective combination of practices to follow in case management and helping health professionals and others involved in case management to develop the required skills to deliver the prescribed services is crucial to the health of the patient.

The Center on Education and Training for Employment, in response to this need, has developed a training guide that details the primary duties, tasks, and steps required in the comprehensive case management of adolescents with chronic diseases. It proposes a team approach to case management which involves the patient and family as key members of the care team along with the physician, nurse, dietitian, psychologist, social worker, and exercise physiologist. The process outlined in the training guide is designed to provide medical, educational, and psychosocial support to help adolescents achieve optimal health and successful transitions to adult care.

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Ray D. Ryan
Executive Director
Center on Education and Training
for Employment

EXECUTIVE SUMMARY

The primary intent of *Case Management of Adolescents with Chronic Disease* is to present a model for optimum delivery of coordinated health care to adolescents with chronic disease and their families. This model is to serve as a guideline to health care professionals working in hospitals, private clinics, public health services, and agencies. It provides a basis for helping them determine the nature and extent of services they currently offer in relation to the model and the specific services that are missing in their case management efforts.

The guide presents the major duties and tasks of case management as identified by a group of ten nationally recognized medical experts in pediatric endocrinology through their participation in a Develop A CurriculUM (DACUM) workshop. Although the panel of experts focused on diabetes as a single chronic disease in detailing the duties and tasks, the resulting Competency Profile reflects a general model for case management of adolescents with chronic disease. Disease-specific information appears only in the task steps, which is appropriate as this is where the details of how to perform each task are specified.

The training guide contains performance objectives for each task relative to training outcomes, not to on-the-job performance. The specific conditions and standards of performance are not specified in this guide, but would appear in future training modules if they were to be developed for use in training professional members of the care team and the patient/family.

The team approach to case management is crucial to the guide's implementation and use. A task verification survey instrument was sent to 100 randomly selected members of the American Diabetes Association listed in the ADA Professional Directory. The responses from this survey indicated the professionals' perceived importance of tasks presented and the team members who typically are most responsible for task completion. The team members noted in the guide as having primary responsibility are those identified as such through the survey; however, the involvement of all team members, including the patient and family, is considered to be important in all tasks.

The *Case Management for Adolescents with Chronic Disease* training guide is designed for use by all health professionals, as well as patients and families, in providing and assuring comprehensive, coordinated health care to adolescents with chronic disease.

INTRODUCTION

Adolescents with chronic disease are a particularly vulnerable group of young people who must cope every day of their lives with a regimen of health care that is intrusive to their bodies as well as lifestyles. As in diabetes, there are no "days off" from chronic disease. The disease must be managed daily with interventions like insulin shots, special diets, regular exercise, and so forth. Training professionals as well as patients and families to manage the clinical, emotional, and psychosocial aspects of disease in relation to their lifestyles is a challenge. This guide presents a structure for such an effort. It offers a detailed outline of the duties, tasks, and steps involved in case management of adolescents with chronic disease, like diabetes.

While not inclusive, some examples of the utility of this document are presented below:

- As an advocacy document of standards to serve as guidelines for the interdisciplinary action of a case management team composed of physician, nurse, dietitian, psychologist, social worker, exercise physiologist, parent, and adolescent

- As a target for care that leads institutions, clinics, etc. to qualify for institutional accreditation by professional associations like the American Diabetes Association

- As a checklist through which institutions, clinics, hospitals, etc. can assess the comprehensiveness of care they are currently providing and set goals for service improvement

- As guidelines for the kinds of support that should be offered on an outreach basis by public health nurses who serve patients in rural areas, as well as suburban and urban settings

- To stimulate interagency communication and collaboration by helping institutions, agencies, etc. to recognize that providing the type of comprehensive services recommended in the model will take resources that some of them do not have and can only be provided by the combined effort of all who serve adolescents with chronic disease.

- As a topic of the ongoing education and training of professional staff of agencies like social service agencies, mental health agencies, and temporary care services to promote understanding of the concept of total case management as related to chronic disease in adolescence and what such case management should entail. The case management approach detailed in the competency profile and training guide could be presented in workshops and advertised through schools of social work, associations, and so forth

- As training for primary care physicians--family practice physicians, pediatricians, general practitioners, and other primary care providers who don't have specialty training--on how to use a specialty team, public health agencies, and other services, as a means of augmenting the care of the adolescent without threatening their patient/client retention

- As a workshop agenda topic. For example, the topic/model could be presented at a meeting for all SPRANS grantees within the state to serve as a basis for initial and ongoing sharing and collaborating among the SPRANS grant recipients

- As a resource to submit to the national Center for Policy Coordination in Maternal and Child Health and included in MCH-NET.

A. ESTABLISH AND MAINTAIN CONTACT

A-1. Identify Target Population.

Performance Objective: At the end of this training module, the case management team member will be able to present a plan for identifying the target population and a schedule for implementing the plan.

Primary Responsibility: Physician, Nurse, Social Worker

Step 1. Develop a list of individuals who have professional contact with adolescents who have diabetes.

a. Obtain names of pediatricians.
b. Obtain names of family physicians and osteopaths.
c. Obtain list of internists.
d. Obtain names of certified diabetes educators.
e. Obtain names of dietitians in diabetes care and education.
f. Obtain list of pharmacies.
g. Obtain list of junior high school and high school nurses.
h. Obtain list of junior high school and high school guidance counselors.
i. Obtain list of public health nurses.
j. Obtain list of DSS or 045 social workers.

Step 2. Establish and use computerized mailing lists to obtain referrals.

a. Have computer tally points serviced by zip code, by school, by diabetologist, and also by primary physician.
b. Upgrade the system yearly.
c. Recontact physicians not referring patients to learn how a cooperative, supportive arrangement can be achieved.

Step 3. Send out letters announcing the program once or twice a year.

Step 4. Use local newspaper ads and public service announcements to reach the general public.

a. Announce opening.
b. Invite participation.
c. Repeat frequently: once weekly for two months and then every two/three months indefinitely or until sufficient referral base is established.
d. Invite newspaper, TV, and radio interviews regarding program.

A-2. Teach patients about the benefits of health supervision.

Performance Objective: At the end of this training module, the case management team member will be able to prepare pamphlets and verbally discuss with patients/families the benefits of regular health care.

Primary Responsibility: Physician, Nurse

Step 1. Offer a pamphlet that presents the benefits of ongoing health supervision.

a. Assemble existing pamphlets designed to promote routine health care visits.
b. Assess the content of all pamphlets to assure that they contain information about . . .

- o the importance of a regular re-evaluation of the patient's health care plan to assure that it accommodates any changes in seasonal activities, work schedule, health problems, life changes, etc.;
- o acute needs: sick days and hypoglycemia emergencies;
- o the prevention of hypoglycemia and DKA;
- o dietary and exercise guidelines; and
- o the theory that early identification and treatment contribute to better outcomes regarding long-term complications.

c. Assess pamphlet design for appeal and appropriateness to target adolescent/family population.
d. Assess reading level of pamphlets.
e. Select or prepare one or two new pamphlets of appropriate content, design, and reading level to use with the target population.
f. Give the pamphlet to patient/family at conclusion of initial visit.

Step 2. Give patient and family appropriate pamphlets available through product and drug suppliers.

Step 3. Discuss key, relevant points with patient during every visit.

a. Describe what the patient can expect at each visit.
b. Describe the tests the physician will give, how often the tests will be given and what the test results will show.
c. Describe information the patient should contribute to the meeting.
d. Describe how all information will be used in designing the patient's individualized health care plan.
e. Discuss the benefits of regular checkups.

A-3. **Teach patients/families how to use the team.**

Performance Objective: At the end of this training module, the case management team member will be able to describe the specialties and functions of every member of the team and how patients can use their services.

Primary Responsibility: Nurse, Physician, Social Worker

Step 1. Describe the functions and specialties of participating team members: primary care physician, diabetologist, nurse/nurse educator, dietitian, psychologist/psychiatrist, social worker, exercise physiologist, and patient/family.

Step 2. Describe the patient's/family's role in relation to the rest of the team.

Step 3. Explain when the patient/family should see the primary care physician and when they should see the specialty team.

Step 4. Instruct patients about when and whom to call for given situations.

Step 5. Inform patients/families about how and where they can reach various members of the team.

Step 6. Present the case management team as a group of medical consultants who care about the patient as an individual and are interested in training him/her how to handle a chronic disease like diabetes.

A-4. **Help patient/family deal with financial barriers.**

Performance Objective: At the end of this training module, the case management team member will be able to present a strategy for helping patients/families overcome financial barriers to care.

Primary Responsibility: Social Worker

Step 1. Assess patient/family for financial barriers to health care, e.g., cost of coming to clinic, cost of phone calls, lack of insurance, etc.

a. Design questions to ask in an interview setting or on an assessment form that will lead patient/family to identify financial barriers to care.
b. Conduct one-on-one discussions and/or interviews with patient/family, respecting confidentiality, to obtain financial information.

c. Establish a system for recording and reviewing information from interviews, questionnaires, and intake records.

Step 2. Determine the extent to which in-house financial policies for fee payment, free care, etc. can accommodate the patient/family.

Step 3. Contact government agencies and/or referral hospitals if appropriate.

A-5. **Establish follow up methods.**

Performance Objective: At the end of this training module, the case management team member will be able to design a system for patient follow up.

Primary Responsibility: Physician, Nurse

Step 1. Set up a computerized reminder system--post card vs. phone call.

Step 2. Establish an appointment system.

a. Establish schedule for routine visits, e.g., three-month intervals.
b. Establish appointment times that accommodate patients/families who cannot or will not be absent from school/work, e.g., after 5:00 p.m. or Saturday appointments.
c. Estimate the length of time to allow for each patient visit, including time patient spends with each professional on the case management team.

Step 3. Employ a receptionist to attend to telephone and mail follow up.

A-6. **Address barriers to contact.**

Performance Objective: At the end of this training module, the case management team members will be able to identify common characteristics of patients/families not keeping in contact and list alternative approaches to effect health care contact.

Primary Responsibility: Nurse, Social Worker

Step 1. Conduct computer analysis at least quarterly.

a. Analyze by zip code.
b. Analyze by type of insurance.
c. Analyze by race.

d. Analyze by sex.
e. Analyze by age.
f. Analyze by SES.
g. Analyze by other dx, e.g., Hx drugs, pregnancy, EtOH.

Step 2. Evaluate characteristics of patients/families who are calling for medical information or advice.

Step 3. Evaluate characteristics of patients/families who are keeping appointments and those who are not.

Step 4. Analyze demographic data to determine any patterns related to various factors.

Step 5. Conduct personal phone calls to investigate reasons why patients are not keeping appointments.

Step 6. Identify ways to counterbalance factors involved.

a. Explore in-house services available, e.g. clinic vans to transport patients/families who lack transportation options.
b. Investigate services of community or government agencies, e.g., public health nurses, special programs that serve chronically ill adolescents and their families, etc.

B. PROVIDE AN INDIVIDUALIZED HEALTH CARE TEAM

B.1 **Assure institutional recognition.**

Performance Objective: At the end of this training module, the case management team member will be able to outline a plan for preparing an application for institutional recognition.

Primary Responsibility: Physician, Nurse

Step 1. Obtain instructional manual from American Diabetes Association.

Step.2 Identify and assemble individuals responsible for various aspects of diabetes care in the institution.

Step 3. Assign tasks for completion of application, including establishment of records and systems required.

a. Determine who will be responsible for each task.
b. Allocate time and resources to enable task completion.

Step 4. Monitor staff progress toward task completion.

Step 5. Submit completed application to ADA.

B-2. **Assure competency of team members.**

Performance Objective: At the end of this training module, the case management team member will be able to detail staff development activities to use in training key professionals to become effective and skilled members of a team.

Primary Responsibility: Physician

Step 1. Establish a job description for each team member in relation to the diabetes team.

Step 2. Select individuals to serve on the team, giving consideration to personality and potential for cohesiveness.

Step 3. Review job descriptions for each team member and describe the interactions required for good teamwork.

Step 4. Present opportunities for group formation through activities like team lunches, a team dinner, or time for team participation in an educational workshop.

Step 5. Require appropriate certification, licensure and board examinations for professional team members, certification of diabetes educators through the American Association of Diabetes Educators.

Step 6. Evaluate team members at least annually.

B-3. **Assess patient and family needs for professional assistance.**

Performance Objective: At the end of this training module, the case management team member will be able to perform informal and formal assessments to determine the types of professional assistance required by patient/family.

Primary Responsibility: Physician, Nurse, Social Worker

Step 1. Through thorough history and physical examination, determine medical specialists required for clinical care of a given patient.

a. Review patient clinical records and other reports.
b. look for red flags that indicate problems, e.g., repeated DKA, vision problems, frequent absences from school.

Step 2. Through combined and separate interviews with the patient and family, determine educational and training assistance required for disease management and adherence.

Step 3. Through questions presented verbally or on a questionnaire, obtain information about patient/family feelings, beliefs, behaviors, economic circumstances, interpersonal relationships, etc. to consider in determining need for psychological evaluation or social services.

Step 4. Through observation of body language, tone of voice, and level of apprehension evident in patient/family interactions, determine need for family counseling or social services.

Step 5. Through discussions about patient's school and work transitions, determine need for vocational or career guidance that accommodates having diabetes.

Step 6. Ask patient/family directly about their perceived needs for counseling, social service assistance, or other professional help.

B-4. Identify the health care team responsible for patient case management.

Performance Objective: At the end of this training module, the case management team member will be able to identify the specific health care team responsible for patient case management.

Primary Responsibility: Physician

Step 1. Determine members of family available as team members to support patient.

Step 2. Identify the patient and family as essential to care.

Step 3. Identify primary care provider and his/her role in prevention as well as acute care.

Step 4. Introduce patient/family to individuals on the team: diabetologist, diabetes educator, dietitian, psychiatrist/psychologist, social worker, education specialist, and other team members available for consultation.

Step 5. Give patient/family a card with names and phone numbers of physicians and other specialists on the team.

B-5. Identify the support team.

Performance Objective: At the end of this training module, the case management team member will be able to identify and establish working relationships with professionals in other specialties who can serve as support to the health care team.

Primary Responsibility: Physician, Nurse, Social Worker

Step 1. Establish and maintain a referral and contact list for the various specialists that support the diabetes care team, i.e., school nurse, podiatrist, ophthalmologist, nephrologist, neurologist, gynecologist, school teacher, public health nurses, and other social service personnel.

Step 2. Develop relationships/agreements among support specialists to coordinate and implement patient referrals.

Step 3. Give the patient and family the names and phone numbers of specialists in their local area, as necessary.

Step 4. Maintain communication with support team regarding patient referrals and follow up.

B-6. **Coordinate the team.**

Performance Objective: At the end of this training module, the case management team member will be able to specify and schedule activities to coordinate the team's case management efforts.

Primary Responsibility: Physician

Step 1. Assure that individual team members understand their roles as members of the team.

Step 2. Develop goals for each team member in relation to patient care.

Step 3. Hold weekly team meetings to discuss patients seen that week, to review patient health status and need for complex interventions, and to solve general coordination problems.

Step 4. Provide information, suggestions, and resources to help team members provide comprehensive, coordinated care to patient/family.

Step 5. Monitor communication among the team members.

Step 6. Establish follow up procedures to determine effectiveness and completeness of actions.

B-7. **Coordinate the patient's case management plan.**

Performance Objective: At the end of this training module, the case management team member will be able to prepare an individualized case management plan for the patient that includes patient/family objectives, estimated timelines, activities and procedures, and specific resources for implementing the plan.

Primary Responsibility: Physician, Nurse, Dietitian, Psychiatrist/Psychologist, Social Worker, Exercise Physiologist, Family, and Patient

Step 1. Hold team meetings after clinic to review the management plan for each patient seen.

Step 2. Develop outcome objectives that address the needs of the patient/family, i.e., educational, clinical, psychological.

Step 3. Identify factors that impinge upon implementation of the plan.

Step 4. Define the time frame within which objectives are to be met.

Step 5. Specify the procedures to be followed and the resources required to achieve the objective.

Step 6. Obtain patient/family input regarding the plan.

Step 7. Establish a contract or agreement with the patient/family to signify acceptance of the individualized case management plan.

B-8. **Facilitate active involvement of patient and family.**

Performance Objective: At the end of this training module, the case management team member will be able to identify at least five ways of involving patient/family in the care and management of the disease.

Primary Responsibility: Nurse

Step 1. Explain central role of patient and family support in management of diabetes.

Step 2. Include the patient/family in determining goals, objectives, and strategies for implementing the patient's individualized case management plan.

Step 3. Provide education and confidence building.

Step 4. Encourage telephone consultation at the time of problems.

Step 5. Support patient in the transition from parental supervision to independence.

Step 6. Provide parents access to programs or classes on parenting that include guidelines for appropriate "letting go" with limits, e.g., driving a car.

Step 7. Inform parents of support groups like Special Kids Need Involved Parents (SKIP) and ways to contact such groups.

Step 8. Hold group meetings periodically with the patient and family to discuss progress made and to evaluate their satisfaction with the diabetes care and with the diabetes management plan.

B-9. **Reassess patient and family needs for professional assistance.**

Performance Objective: At the end of this training module, the case management team member will be able to prepare a plan for the periodic, regular, and structured reassessment of patient and family needs.

Primary Responsibility: Physician, Nurse, and Social Worker

Step 1. Determine intervals at which patient/family should be reassessed.

Step 2. Identify the factors to be assessed, e.g., clinical, educational (diabetes management concepts and skills), school attendance and performance, family functioning, financial issues, and so forth.

Step 3. Identify any assessment instruments, forms, or questionnaires to be used.

Step 4. Conduct informal and formal types of assessment detailed in B-3 to obtain information for use in assessing patient/family needs.

B-10. **Anticipate and plan transition to adult health care team.**

Performance Objective: At the end of this training module, the case management team member will be able to prepare a checklist of procedures for transferring patients to the adult health care team.

Primary Responsibility: Physician, Nurse, Social Worker

Step 1. At each visit, ask older adolescents about their plans regarding work or further schooling and living away from home.

Step 2. Determine older adolescent's level of comfort in the pediatric clinic setting and preference for moving to adult health care.

Step 3. Explain difference between adult oriented care and pediatric care in relation to expectations of patient's compliance and maturity.

Step 4. Refer female patients to gynecologist/obstetrician for contraception or other gynecological needs when physically and/or emotionally ready.

Step 5. Assist patients in their transfer to internists or other adult physicians.

a. Recommend several local physicians for patients to select among.
b. Contact or have patient contact the physician's office for an appointment.

Step 6. Summarize records for the adult care team, and copy patient, so that he/she knows what information is being transmitted and what problems are being made known to the adult physician.

Step 7. Ask for follow-up information on the patient after transfer to the adult system as feedback information and to indicate to the patient your continued interest.

C. PROVIDE DISEASE MANAGEMENT EDUCATION AND PROMOTE RESPONSIBLE SELF-CARE

C-1. Assess knowledge, skills, attitudes and beliefs.

Performance Objective: At the end of this training module, the case management team member will be able to prepare a list of interview and test questions to ask as a means of assessing patient/family knowledge, attitudes, and beliefs regarding the chronic disease.

Primary Responsibility: Nurse

Step 1. Interview the patient/family to obtain information about the them and their understanding of diabetes and to establish rapport.

a. Be attentive to the implied as well as spoken word.
b. Learn patient/family knowledge of diabetes through personal history of diabetes, incidence of diabetes in family, etc.
c. Encourage patient to express fears, anxieties, and beliefs.
d. Determine any misinformation harbored by patient and family.
e. Learn the educational background of the family, including siblings.

Step 2. Discuss patient/family attitudes and beliefs to determine their affect on disease management.

a. Learn patient and family expectations about who does what and determine if those expectations are reasonable.
b. Learn patient/family beliefs about what management will do for the patient, e.g., Does the patient/family believe "x" is beneficial to patient health.
c. Determine if cultural or religious beliefs are affecting management.
d. Determine patient/family beliefs about perceived responsibility for self management.

Step 3. Question the patient/family to learn about the patient's prior experience with diabetes--e.g., behaviors that prevent him/her from doing well, ways he/she negotiates care, family functioning, etc.

Step 4. Give patient and family a knowledge test to determine knowledge about diabetes and diabetes management, including meal planning and exercise, if the patient has received previous education and care for diabetes.

Step 5. Ask patient and family to demonstrate the skills necessary for survival if patient has received previous education and care for diabetes.

C-2. **Ensure learning of basic disease management skills.**

Performance objective: At the end of this training module, the case management team member will be able to teach, motivate, monitor, and evaluate patient/family understanding and performance of disease self-care and management techniques.

Primary Responsibility: Nurse, Dietitian

Step 1. Conduct individualized education and training for patient and family while patient is in hospital.

a. Provide instruction about why and how to monitor blood glucose; administer insulin; prevent and treat hypoglycemia; select foods and estimate quantities; and adjust insulin, food intake, or both for changes in usual exercise and eating patterns. (See the ADA educational and clinical goals for treatment.)
b. Provide instruction about basic nutrition/diet issues, including weight control, meal planning, eating of fast foods and so forth.
c. Provide instruction about the importance of consistent exercise in a total health plan and the relationship between exercise, food intake, and insulin administration.

Step 2. Monitor and evaluate patient's knowledge and skill in diabetes management through written tests and skill demonstrations on a regular basis.

Step 3. Conduct telephone follow-up at least once between initial 3-month visits to learn blood-sugar levels and other clinical information.

Step 4. Provide re-education if patient is deficient in knowledge or skill.

Step 5. Recommend computer programs that teach basic and advanced skills to certain patients as appropriate.

Step 6. Introduce motivational interventions like diabetes summer and sport camps, workshops/seminars for adolescent patients who have diabetes, etc. and target them to specific age groups, e.g., middle school youth, high school youth, young adults entering college or work.

C-3. **Assess learning capabilities and styles.**

Performance Objective: At the end of this training module, the case management team members will be able to list criteria for determining patient's ability to learn disease management concepts and skills.

Primary Responsibility: Nurse, Psychologist

Step 1. Review the results of knowledge and skills tests.

Step 2. Use clinical judgment regarding patient's level of reasoning, i.e., their ability to abstract information.

Step 3. Conduct structured and unstructured interviews with patient and family to identify barriers to learning.

Step 4. Review educational evaluation in team conference.

Step 5. Call school counselor to learn if the patient is in a special education class or has some other problem if review indicates reason for concern.

Step 6. Use or obtain from other professionals the results of standardized tests that assess cognitive development and personality traits as necessary.

a. Use ability instruments to measure overall ability, including general intelligence, achievement, aptitude, and reading ability. Example: General Aptitude Test Battery (GATB).
b. Use personality inventories to assess emotional, social, and motivational aspects of an individual. (Examples: Meyers-Briggs Type Indicator (MBTI), and the Sixteen Personality Factor Questionnaire (16 PF).

C-4. **Teach advanced self-care skills for flexible disease management.**

Performance Objective: At the end of this training module, the case management team member will be able to prepare and present education programs that employ a variety of instructional techniques and that include materials that are written at an appropriate reading level, are competency based, and are consistent with approved educational standards.

Primary Responsibility: Nurse, Physician

Step 1. Provide continuing education on an outpatient basis to patient, family, grandparents, baby-sitters, siblings, special friends and other caregivers.

a. Follow ADA standards for patient education.
b. Teach insulin preparation and dosage, sick day management and DKA, pathophysiology, and management of hypo/hyperglycemia.
c. Teach ways to minimize painful injections.
d. Teach the importance of good hygiene.
e. Teach how to adjust baseline insulin and to alter pre-meal regular in accordance with glucose levels.
f. Introduce new supplies as they become available, e.g., the Boehringer Mannheim Merlin (a computerized management system).

Step 2. Use a variety of teaching methods--lecture, problem solving, demonstration, and dis[illegible]

Step 3. Offer instruction in a variety of settings--group, individual, one-on-one.

Step 4. Sequence topics logically from simple to complex, beginning with survival skills.

Step 5. Assure instruction is appropriate to the age, developmental stage, and cognitive ability of the adolescent and his/her family.

a. Obtain and review educational materials available for patients and families.
b. Use the Fog Index to conduct a reading level check on all printed patient/family information, curriculum, and written tests to determine if they are readable to the patient/family.
c. Obtain and/or prepare several versions of written materials/tests to accommodate the diverse reading levels of patients/families. For example, many educationally or economically disadvantaged people cannot read above the third-grade reading level; some patients have Limited English Proficiency and cannot read at all.
d. Provide hands on as well as verbal/written experiences since many people, including those who are handicapped or otherwise disadvantaged, are governed by the right hemisphere of the brain and therefore learn by doing rather than interpreting.

Step 6. Use quality, multimedia educational materials, e.g., Learning to Live Well with Diabetes by Donnell Etzweiler, et al., a guide for individuals and families with diabetes that was developed and published by the International Diabetes Center, and Diabetes and Living Well, a videotape produced by the Greater Boston Diabetes Association.

Step 7. Provide special programs targeted to special populations.

Step 8. Offer parent and sibling education classes and support group options.

Step 9. Help patients/families to develop an individualized diabetes knowledge and management plan that details patient/family objectives and competency-based evaluation criteria.

Step 10. Help patient/family educate school personnel and employers about diabetes.

C-5. **Teach creative meal planning for a flexible lifestyle.**

Performance Objective: At the end of this training module, the case management team member will be able to present verbal and written information on meal planning, preparation, and adjustment for a flexible lifestyle.

Primary Responsibility: Dietitian

Step 1. Develop with patient/family a written individualized meal plan that is as appropriate to management goals and lifestyle as possible.

Step 2. Present information on nutritional advances, e.g., artificial sweeteners, low fats, low cholesterol foods, high fiber foods, etc.

Step 3. Address issues like eating out, eating at fast food restaurants, eating refreshments at parties, snacks.

a. Give patient/family written guidelines, e.g., Exchange Lists for Meal Planning, Healthy Food Choices, Constant Carbohydrate Diet Instruction.
b. Present strategies for coping with peer pressure to deviate from management plan.

Step 4. Teach advanced meal planning skills including recipe adaptations, label reading, restaurant and holiday eating, and so forth.

Step 5. Discuss ways to adjust food intake to accommodate irregular meals and schedules.

Step 6. Discuss precautions regarding use of alcohol.

Step 7. Explain how extra calories can counteract effect of increased exercise.

Step 8. Teach adjustment of calories to accommodate growth needs, weight control, etc.

Step 9. Explain diet adjustment required for sick days.

Step 10. Recommend magazines and cookbooks that have recipes and meal plans for adolescents with diabetes.

C-6. **Teach interaction of adolescent body changes, behaviors, and psychosocial status with the chronic disease.**

Performance Objective: At the end of this training module, the case management team member will be able to explain the effects of growth, exercise and stress on the body's reaction to the chronic disease and provide guidelines to ensure safe practices.

Primary Responsibility: Physician, Nurse, Dietitian, Social Worker, Exercise Physiologist, and Psychologist.

Step 1. Determine the best time to hold the class/teaching session so that all members of the team can be present. (After the clinic visit is one time to be considered.)

Step 2. Coordinate content and timing with other instructional programs on survival skills and nutrition.

Step 3. Present information and guidelines about insulin therapy and monitoring techniques during growth years, e.g., ways to prevent low blood sugar through diet, exercise, and insulin adjustment.

Step 4. Present information and guidelines for a safe program of regular exercise based on those presented in the Physician's Guide to Insulin-Dependent (Type I) Diabetes, American Diabetes Association.

Step 5. Present information on stress and its potential affect on the immune system and on clinical outcomes.

Step 6. Develop handouts/materials for use as appropriate.

Step 7. Provide opportunities for group interaction and discussion about real-life problems and how to deal with them.

Step 8. Offer encouragement and support through activities and programs that bring adolescents with diabetes together for fun, education, and discussion.

C-7. **Expose patient to instructional materials that help them to minimize the consequences of potentially dangerous adolescent behaviors.**

Performance Objective: At the end of this training module, the case management team member will be able to review, select, obtain and/or develop instructional materials to help adolescents with chronic disease avoid potentially dangerous behaviors.

Primary Responsibility: Nurse, Psychologist

Step 1. Review materials available through the ADA, from product and drug companies, and from educational institutions and publishers.

Step 2. Select materials that are appropriate for the adolescent population and that address the life issues important to their age group, e.g., self esteem, sexual activity and pregnancy, stress management, assertiveness training, etc.

Step 3. Select materials that offer a variety of teaching methods and media options.

Step 4. Present a variety of materials that include "take home" handouts, role playing activities for group interaction, and so forth.

a. Give handouts like snack/exchange lists, sick day foods, and foods to use on special occasions.
b. Give problem solving worksheets on exercise, diet and insulin adjustments.

Step 5. Recommend magazines like Diabetes Forecast and The Diabetes Educator as appropriate to patients and families.

C-8. **Teach about the long-term consequences of the chronic disease.**

Performance Objective: At the end of this training module, the case management team member will be able to prepare a lesson plan for teaching about the long-term complications of chronic disease on the body's systems and organs.

Primary Responsibility: Nurse, Physician

Step 1. Present general and patient-specific information related to long-term complications.

a. Inform the patient about what is known and unknown about blood glucose control and complications.
b. Inform patient/family about the importance of controlling risk factors, e.g., blood, fats, obesity, smoking, and hypertension.

Step 2. Identify the major organs affected by diabetes and describe how to slow or prevent and detect/treat complications, e.g., have an eye examination once a year.

Step 3. Present information in a positive manner.

a. Present basic information, responding in detail only when questioned by the patient or when symptoms are evident.

b. Do not use fear of long-term consequences as a motivating factor.
c. Present hope/likelihood that new treatment will reduce complications of retinopathy, nephropathy, neuropthy, and reduce risk for cardiovascular disease.

Step 4. Present examples from articles in magazines like the Diabetes Forecast, which report on persons with diabetes mountain climbing and otherwise leading active, full lives as "knowledgeable persons with diabetes."

Step 5. Invite persons who are successful and popular role models to serve as guest speakers for training sessions, conferences, or special programs held for adolescents with diabetes.

Step 6. Invite persons who are successful and popular role models to serve as guest speakers for training sessions, conferences, or special programs held for adolescents with diabetes.

Step 7. Recommend 1-2 reference books to mature adolescents/families who request additional information, e.g., Learning to Live Well with Diabetes by Donnell Etzweiler, et al., and Diabetes Mellitus in Children and Adolescents by Luther B. Travis, et al.

C-9. Teach the art of negotiating for self-management and responsibility.

Performance Objective: At the end of this training module, the case management team member will be able to list the major points to be covered in negotiating for self management and responsibility and at least three activities to support skill development in this area.

Primary Responsibility: Psychologist, Social Worker, Nurse

Step 1. Utilize group process activities involving the nurse, social worker and psychologist, along with other appropriate team members.

Step 2. Offer guidelines, examples, and activities to promote appropriate compromise.

Step 3. Separate negotiating for diabetes from negotiating for other adolescent concerns.

Step 4. Establish patient and/or family group programs to address such topics as parenting skills, independence, etc.

C-10. **Teach about the adult care system.**

Performance Objective: At the end of this training module, the case management team member will be able to identify and describe the patient's responsibilities in the adult health care system.

Primary Responsibility: Nurse, Physician

Step 1. Identify the professionals that compose an adult health care team.

Step 2. Inform patient of potential physician/program options.

Step 3. Identify patient's responsibility in assuring coordinated, comprehensive care, e.g., to make sure ophthalmologist report is received by diabetologist.

Step 4. Give patients a list of strategies for effective interactions with the adult care team, e.g., what to tell or ask the doctor/nurse, how and when to be assertive, etc.

Step 5. Alert patients of the need to investigate insurance coverage after age 21.

C-11. **Provide genetic counseling.**

Performance Objective: At the end of this training module, the case management team member will be able to present facts about the role of genetics in chronic disease.

Primary Responsibility: Physician

Step 1. Explain the role of inheritance (what is known and unknown) to newly diagnosed patients.

Step 2. Inform patient of possible risk of occurrence in offsprings, making sure your information is current and accurate.

Step 3. Offer additional information as requested by patient.

Step 4. Offer special programs (or involve community groups like the local chapter of ADA) where guest speakers present information on the latest research regarding genetics in diabetes.

C-12. **Provide preconception medical and psychological counseling.**

Performance Objective: At the end of this training module, the case management team member will be able to explain the relationship between metabolic control and pregnancy risks and offer guidance and reassurance as indicated.

Primary Responsibility: Physician, Nurse

Step 1. Discuss with patient the importance of excellent metabolic control before and during pregnancy.

Step 2. Discuss birth control options and the risks associated with each in relation to diabetes.

Step 3. Recommend and prescribe appropriate birth control.

Step 4. If pregnancy is desired, attempt to improve metabolic control, often using intensive medical therapy.

Step 5. Evaluate maternal complications, e.g., risk of malformation.

Step 6. Counsel patients regarding nature and risk for malformation as relates to metabolic control.

Step 7. Reassure patients, when appropriate, of positive outcomes of pregnancy and baby when diabetes is well controlled.

Step 8. Counsel patient regarding complications of poor diabetes control during the latter stages of pregnancy.

Step 9. If pregnant, provide appropriate options and access to facility for either continuation or termination of pregnancy.

Step 10. Guide female patients to select a gynecologist that is experienced in medical care for women with diabetes.

C-13. **Periodically reassess and reeducate as necessary.**

Performance Objective: At the end of this training module, the case management team member will be able to detail a plan for the periodic reassessment and reeducation of patient/family.

Primary Responsibility: Nurse

Step 1. Develop an knowledge assessment instrument to assess state of diabetes knowledge.

Step 2. Establish regular intervals for reassessing diabetes knowledge for both family and patient

a. Assess at transition to middle school.
b. Assess at transition to high school.
c. Assess at beginning of senior year in h.s.

Step 3. Develop instrument to regularly assess the degree of self-management being assumed by the patient.

Step 4. Design and implement formal educational programs to address specific needs.

Step 5. Recommend and explain the use of computer diabetes programs that patients could use on their own.

Step 6. Carry out informal educational updates during the regular medical care program.

C-14. **Transfer to adult health care system.**

Performance Objective: At the end of this training module, the case management team member will be able to list the steps involved in transferring a patient to an adult care physician/team.

Primary Responsibility: Nurse, Physician, Social Worker

Step 1. Evaluate most appropriate health care setting for patient given personalities, resources available with the health care team, and psychological status.

Step 2. Arrange referral to adult care physician.

Step 3. Transfer patient records to physician.

D. IMPROVE PATIENT'S HEALTH STATUS

D-1. Evaluate and improve metabolic control.

Performance Objective: At the end of this training module, the case management team member will be able to list procedures for evaluating long-term and short-term glycemic patterns and describe recommended insulin therapy.

Primary Responsibility: Physician

Step 1. Determine long-term glycemic (glycosylated hemoglobin), and lipid (cholesterol, HD Cholesterol) profiles at least biannually.

Step 2. Identify and assess contributory risk factors (e.g., family history, coronary heart disease).

Step 3. Determine short-term glycemic pattern through self-blood glucose monitoring.

Step 4. Determine and adjust optimal insulin doses/therapy as required.

D-2. Encourage optimal emotional growth.

Performance Objective: At the end of this training module, the case management team member will be able to perform activities that promote patient self-confidence and self-esteem.

Primary Responsibility: Psychologist, Physician, Social Worker, Nurse

Step 1. Assess developmental level, vulnerabilities, and strengths.

Step 2. Encourage developmentally appropriate self-management behavior as a means of improving self-confidence and self-esteem.

Step 3. Encourage patients/families to express their feelings and fears about having diabetes.

Step 4. Offer guidelines for positive interactions for given family systems with various levels of functioning.

a. Keep informed of current issues and research. For example, read "Behavioral Issues in Patients with Diabetes Mellitus with Special Emphasis on the Child and

Adolescent" by Allan Drash and Dorothy Becker, in Ellenberg and Rifkin's Diabetes Mellitus: Theory and Practice, 1989.

b. Present all recommendations to patient/family in a positive, nonjudgmental manner.

Step 5. Counsel/refer those with behavioral/emotional problems.

D-3. Assess physical growth and development.

Performance Objective: At the end of this training module, the case management team member will be able to obtain, chart, and evaluate measurements of patient height, weight, and blood pressure and recommend treatment for patients with problems.

Primary Responsibility: Physician, Nurse, Dietitian

Step 1. Conduct yearly physical exams with measurement of weight, blood pressure, stage of sexual maturation.

Step 2. Chart height and weight measurements on standardized growth charts every 3-4 months.

Step 3. Evaluate and treat patients whose growth is deviant.

Step 4. Evaluate and treat patients with nutritional problems, e.g., changes in appetite, food intolerances, excessive weight fain or loss, use of alcohol, and eating disorders.

D-4. Promote physical fitness.

Performance Objective: At the end of this training module, the case management team member will be able to prepare with the patient an exercise plan that includes exercise choice, preparation, intensity, and safety measures.

Primary Responsibility: Nurse, Physician, Dietitian, Exercise Physiologist

Step 1. Educate and counsel about importance of exercise regarding glycemic control, weight control, mental outlook, and cardiovascular risk factors.

Step 2. Encourage regular exercise that is appropriate to patient's age, lifestyle, physical condition, and motivation.

Step 3. Present strategies for avoiding hypoglycemia from exercising.

a. Instruct in methods of timing diet and insulin injection to exercise periods.
b Instruct patient to inject insulin away from the exercising limbs of the body.
c. Instruct patient to carry fast-acting carbohydrates to use in case of insulin reaction.

Step 4. Encourage prudent lifestyle.

Step 5. Encourage teamwork at school.

Step 6. Plan with patient/family the type of intensity, frequency, and duration of exercise to be followed.

D-5. **Promote healthy dietary practices.**

Performance Objective: At the end of this training module, the case management team member will be able to summarize recommended nutrient composition regarding calorie, carbohydrates, fiber, protein, sodium, and vitamins and minerals.

Primary Responsibility: Dietitian

Step 1. Encourage appropriate ADA calorie intake.

Step 2. Limit sodium intake.

Step 3. Limit saturated fat intake.

Step 4. Encourage higher fiber diet.

Step 5. Promote protein sources that are low in total fat, saturated fat, and cholesterol.

Step 6. Emphasis the importance of patient/family ability to incorporate nutritional intervention into daily meal planning and lifestyle.

Step 7. Express confidence in the patient's ability to follow healthy eating practices.

D-6. **Evaluate for disease-related complications.**

Performance Objective: At the end of this training module, the case management team member will be able to list the signs, symptoms, and specific exam procedures for detecting retinopathy, neuropathy, nephropathy, macro-vascular disease, and limited joint mobility.

Primary Responsibility: Physician

Step 1. Perform funduscopic exam each visit and refer to ophthalmologist for yearly exam when duration of diabetes approaches 5 years.

Step 2. Perform yearly urine examination for microalbumin (insipient nephropathy) and renal functions as indicated.

Step 3. Monitor blood pressure yearly (or more often if needed).

Step 4. Obtain history for neuropathy (peripheral and autonomic) and examine as indicated.

Step 5. Examine feet at each exam; support good skin and foot care.

Step 6. Examine hands and joints to detect limited joint mobility.

Step 7. Examine injection sites.

Step 8. Monitor for autoimmune complications.

D-7. **Treat chronic disease complications.**

Performance Objective: At the end of this training module, the case management team member will be able to list the complications treatable by the care team and those that require referral to other specialists/support team.

Primary Responsibility: Physician

Step 1. Treat hypertension.

Step 2. Refer and assure follow up for retinopathy.

Step 3. Refer for skin/feet lesions.

Step 4. Treat hyperlipidemia.

Step 5. Treat associated endocrine different states.

D-8. **Address risk factors of tobacco, alcohol, drug abuse, and sexual activity.**

Performance Objective: At the end of this training module, the case management team member will be able to introduce objective and correct information regarding risk factors that affect chronic disease outcomes in a nonjudgmental manner.

Primary Responsibility: Physician, Nurse, Social Worker

Step 1. Identify the effects of alcohol, tobacco, and drugs in relation to diabetes and to the individual.

a. Obtain pamphlets on the topics to give to patient/family, e.g., When a Woman Smokes, American Cancer Society; Me Quit Smoking? Why?, American Lung Association; and Drug Abuse: A Realistic Primer for Parents, Do It Now Foundation.
b. Use resources that list and describe the effects of various risk factors, e.g, Pediatric and Adolescent Diabetes Mellitus by Stuart J. Brink.

Step 2. Discourage cigarette and drug use; refer substance abusers for treatment.

Step 3. Encourage moderation of alcohol intake and offer guidelines for use.

Step 4. Identify sexually active adolescents.

Step 5. Counsel regarding contraception; assure contraception for sexually active youth.

Step 6. Educate regarding genetic and metabolic risk of pregnancy.

E. ASSURE APPROPRIATENESS OF PATIENT EQUIPMENT

E-1. Assess patient's particular supply and equipment needs.

Performance Objective: At the end of this training module, the case management team member will be able to identify basic and supplementary supplies/equipment that patients need for health care.

Primary Responsibility: Nurse

Step 1. Identify specific supplies/equipment patient requires.

Step 2. Assure that new patients receive the basic supplies of insulin, syringes, glucagon, cleansing alcohol, swabs, lancets or finger sticking devices, and strips for SMBG.

Step 3. Make sure patient has medical emergency identification to wear.

Step 4. Recommend additional supplies/equipment to patients as appropriate and beneficial, e.g, NOVO insulin pen, jet injectors, equipment for persons with other disabilities like blindness, etc.

E-2. Identify sources of supplies and equipment.

Performance Objective: At the end of this training module, the case management team member will be able to list the names, benefits, and sources of products and the pharmacies that stock and provide service for them.

Primary Responsibility: Nurse

Step 1. Meet with product and drug sales representatives to learn about new products and the benefits of using them.

Step 2. Inform patient and family of local pharmacies that provide service as well as supplies and equipment.

Step 3. Inform family and patient of how to contact manufacturers if problems arise.

Step 4. Make sure patient and family are aware of limits of warranty.

Step 5. Assist patients who require special arrangements to acquire supplies/equipment.

E-3. **Ensure that equipment works.**

Performance Objective: At the end of this training module, the case management team member will be able to list points to check to determine if equipment works properly.

Primary Responsibility: Nurse

Step 1. Have patient/family bring equipment to first checkups to demonstrate their ability to use it.

Step 2. Allot time periodically for quality assurance and evaluation of patient meter and skill techniques, e.g., Has the meter been kept clean?

Step 3. Make sure patient and family know how to troubleshoot equipment problems/failure.

E-4. **Periodically reassess patient's equipment needs.**

Performance Objective: At the end of this training module, the case management team member will be able to list the kinds and characteristics of available equipment and the population (age, lifestyle, etc.) each accommodates.

Primary Responsibility: Nurse

Step 1. Take into account the patient's changing life style, e.g., transition into college or employment situations.

Step 2. Be informed of new supplies and equipment that may be appropriate for the patient in transition, including those that are computer based.

F. PROVIDE PSYCHOLOGICAL SUPPORT

F-1. **Assess school performance and cognitive, social, and emotional status of patient and family.**

Performance Objective: At the end of this training module, the case management team member will be able to prepare a list of patient/family interview questions and observations, a clinical record form on which to record such information, and criteria for assessing psychiatric counseling needs.

Primary Responsibility: Psychologist, Social Worker

Step 1. Conduct personal interviews with the patient and his/her family to obtain information and to maintain communication and patient/team rapport.

a. Ask open-ended questions about family, primary caregiver, family dynamics and communication, friends, school performance, absenteeism, behavior at school and home, and attitudes and feelings.
b. Record information on patient forms and/or ask patients to record answers to a prepared interview questionnaire.

Step 2. Observe the patient/family behaviors, attitudes, expressions, and communication patterns.

Step 3. Record significant information on clinic record forms.

Step 4. Analyze information gathered through interview and observation.

Step 5. Provide or refer patient for psychiatric follow up or counseling as necessary.

Step 6. Periodically reassess patient/family.

F-2. **Promote positive self-image and patient optimism to master the requirements of diabetes and to achieve victorious living (life goals).**

Performance Objective: At the end of this training module, the case management team member will be able to describe at least 5 ways to promote patient self-image and sense of optimism.

Primary Responsibility: Physician, Psychologist, Social Worker, Dietitian, Exercise Physiology

Step 1. Present all health-related information in a positive manner.

Step 2. Exhibit a positive attitude regarding patient's health, education, employment, and social future.

Step 3. Purposefully say and do things to boost patient's self-esteem, e.g., compliment, express confidence in patient's abilities, and so forth.

Step 4. Teach parents to positively reinforce adolescent's diabetes-care behavior.

F-3. **Promote appropriate social support networks.**

Performance Objective: At the end of this training module, the case management team member will be able to design flyers, bulletins, and newsletters announcing special camps, programs, and support groups.

Primary Responsibility: Social Worker, Psychologist, Nurse

Step 1. Identify special camps and programs offered by the ADA for adolescents of various ages.

Step 2. Offer special outings/activities for patients to build comraderie among them.

Step 3. Offer and/or refer parents to patient support groups.

Step 4. Distribute flyers to patients and families announcing activities and events at clinic visits and through mailing lists obtained from the ADA.

Step 5. Post flyers and special bulletins in patient visiting area.

Step 6. Send letters to the targeted patient group promoting age specific and topic specific activities and events.

F-4. **Identify and address psychosocial causes of poor control.**

Performance Objective: At the end of this training module, the case management team member will be able to demonstrate, through role play, the interviewing of patient and family to learn psychosocial causes of poor control and counsel them toward problem solution.

Primary Responsibility: Psychologist, Social Worker

Step 1. Conduct an in-depth investigation of patients who are doing poorly by asking patient and parent separately questions about the following:

a. Ask questions about economic issues: "Do you have the supplies and equipment you need?" "Do you find the food on this diet expensive?"
b. Ask questions about family: "How would you describe your family?" "How do you get along with your parents? siblings?" "How are things between your mom and dad?"
c. Ask questions about feelings: "What is it like to have diabetes?" "What is the worse thing about it?"
d. Ask questions about specific diabetes management behaviors: "Do you ever forget injections?" "Are you ever late with your injections?" "When is it hardest for you to test your blood? to follow your diet?" "Do you sometimes questions or estimate what your blood sugar is?"
e. Ask questions about behaviors: "Do you smoke? take drugs?" "Do you have a boy/girl friend?" "How often do you sleep together?" "What do you know about sexually transmitted disease?"

Step 2. Discuss all questions in an empathetic nonjudgmental manner.

Step 3. Discuss problems with the family, helping them explore options and ways to resolve the problems.

Step 4. Take steps to remedy situations when the patient and/or family can't or won't take corrective action, e.g., contacting youth services to get patient placed in another home setting or assign a visiting nurse to see that the patient receives medicine.

F-5. **Ensure mental health interventions in cases of recurrent medical crises.**

Performance Objective: At the end of this training module, the case management team member will be able to describe how team members can assist the psychiatrist in designing mental health interventions for patients in crisis.

Primary Responsibility: Physician, Psychologist

Step 1. Refer patient for psychiatric evaluation in case of recurrent DKA or recurrent severe hypoglycemia as this frequently indicates severe psychiatric problems in child, family, or both.

Step 2. Provide psychiatrist with information on patient's medical background and diabetes history.

Step 3. Offer to serve as a consultant on medical issues.

Step 4. Request results of psychiatric evaluation after obtaining release of information from patient/family.

F-6. **Identify psycho-pathology including depression, eating disorders, separation anxiety, psychosis, suicide, school absenteeism, and work absenteeism, and refer for treatment.**

Performance Objective: At the end of this training module, the case management team member will be able to describe an interview process for identifying instances of psycho-pathology in patients.

Primary Responsibility: Psychologist, Social Worker, Physician

Step 1. Look for behaviors common to adolescents with diabetes, e.g., 50% of adolescents with diabetes will have depression; anorexia is 3-4 times more common in adolescents with diabetes.

Step 2. Use personal skills, empathy, and nonjudgmental manner when relating to patients/family.

Step 3. Use appropriate psychiatric paper/pencil tests to verify or further detect conditions in patients who are suspect.

Step 4. Involve a mental health professional in analysis and treatment.

F-7. **Provide crisis counseling when needed.**

Performance Objective: At the end of this training module, the case management team member will be able to outline a strategy for crisis counseling, identifying activities, time, and staff involved.

Primary Responsibility: Psychologist, Social Worker

Step 1. Offer 24 hour service to patients.

Step 2. Assure qualified staff are on call. Example: At night, an intern may be on call in the hospital but the intern must know the specific pediatrician or pediatric endocrinologist to contact if necessary.

Step 3. Provide 24 hour availability of social worker and psychiatrist also.

Step 4. Provide supportive counseling to patients/families in crisis routinely at diagnosis and during a metabolic emergency to facilitate coping and return to functional state.

Step 5. Include crisis phone numbers and names on the form patients use to record their daily blood sugars.

F-8. Negotiate changing family roles.

Performance Objective: At the end of this training module, the case management team member will be able to role play with patient and family ways to negotiate changing family roles.

Primary Responsibility: Psychologist, Social Worker, Nurse

Step 1. Observe patient/parent stresses.

Step 2. Assist the patient/family with changing roles as the adolescent gradually assumes more diabetes tasks and the parent assumes a consultant, supervisory role.

Step 3. Counsel parents and patients on how to negotiate differences in regard to diabetes goals and expectations.

Step 4. Recommend parent seek information and skill in behavior modification techniques if appropriate.

Step 5. Encourage a problem-solving approach to decision making with parents/patient working as a team, discussing such issues as how overnights and parties are to be handled.

Step 6. Make family counseling available if possible.

F-9. Follow up on recommendations and referrals.

Performance Objective: At the end of this training module, the case management team member will be able to list ways to conduct and record information about follow up on recommendations and referrals.

Primary Responsibility: Nurse, Psychologist, Social Worker

Step 1. Relate and confirm action during case management team meetings regarding inpatient adolescents with diabetes.

Step 2. Designate responsibility for coordinating follow up for out-patients to the clinical social worker.

Step 3. Establish checkpoints for confirming follow up.

Step 4. Record follow up information on appropriate records.

F-10. **Assure adequate on-going communication among all team members in chronic situations.**

Performance Objective: At the end of this training module, the case management team member will be able to list at least 5 ways to assure on-going communication among all team members in crisis situations.

Primary Responsibility: Physician, Nurse, Psychologist, Social Worker

Step 1. Conduct regular, weekly team meetings.

Step 2. Overcome limits imposed by the "confidentiality" issue to the point that the physician and other appropriate team members know about conditions that are crucial to treatment and care.

Step 3. Find ways to learn and report key psychological factors affecting health, like excess stress at home, so appropriate care and regimen can be prescribed.

a. Call school regarding school records with parents approval as necessary.
b. Conduct home visits with patient/family.

Step 4. Share information about patient's attendance in referral service, such as therapy, with other members of the team.

F-11. **Provide prospective psychosocial assessment and preventive counseling in new onset and high risk families.**

Performance Objective: At the end of this training module, the case management team member will be able to identify the counseling methods or assessment instruments to be used in detecting factors that put patients at risk.

Primary Responsibility: Psychologist, Social Worker

Step 1. Use counseling skills to conduct patient/family psychosocial interviews and assessments.

Step 2. Develop or obtain psychosocial assessment instruments to detect factors that could put a patient at risk for adherence or adjustment problems.

Step 3. Assist family in reducing risk factors, i.e., help develop support for single parents, provide counseling if parent/adolescent relationship is dysfunctional.

G. ADDRESS ECONOMIC AND SOCIAL NEEDS

G-1. Assess economic and social service needs and link to resources.

Performance Objective: At the end of this training module, the case management team member will be able to list questions to ask patients/families and other team members to determine the social, economic, and emotional needs of the family and present strategies for helping them obtain the services they need.

Primary Responsibility: Social Worker

Step 1. Establish rapport with family.

Step 2. Interview the parents regarding family structure, employment, insurance, welfare benefits, family health, and psychological status, adolescent behavior or learning problems, and cultural influences.

Step 3. Review patient chart for consistency of information.

Step 4. In a team meeting, review the information obtained through all interviews with patients/families and on the patient chart.

Step 5. Learn other agencies and systems patient and family are involved in and get releases from patient to obtain relevant information from those outside agencies.

Step 6. Identify any social, economic, and emotional needs of family and other caregivers.

Step 7. Identify social services and community services to which patients can turn for help.

Step 8. Develop a plan to link patient/family with groups that provide the services they need.

Step 9. Find or create ways to help patients cope with the economic costs of the illness and make good decisions, e.g., Where will family stay overnight if they don't live near the hospital and have no money for motels? How will the family provide for out-of-pocket expenses such as phone calls to the hospital/center, meals when visiting the inpatient or for outpatient appointments, gas money, etc.

G-2. **Plan for adult health care coverage.**

Performance Objective: At the end of this training module, the case management team member will be able to outline strategies for helping patients/families plan for health care coverage.

Primary Responsibility: Social Worker, Physician

Step 1. Discuss costs, employment, and other factors that affect the type of health care coverage available to persons with diabetes.

Step 2. Refer mature adolescents and family to appropriate insurance providers--college/university health insurance systems, family insurance company, employer's insurance plans--to learn benefits and coverage for persons with diabetes.

Step 3. Provide for additional education about the costs of health care coverage by offering workshops/speakers or by involving local chapters of the ADA in offering such programs.

G-3. **Provide for vocational advice and career counseling.**

Performance Objective: At the end of this training module, the case management team member will be able to list the names and phone numbers of school counselors, and vocational centers, who are qualified to counsel adolescents with chronic disease in vocational and career issues.

Primary Responsibility: Social Worker, Nurse

Step 1. Contact the school guidance personnel of the patient's school to determine their capacity for counseling persons with chronic diseases on vocational/career issues.

a. Develop or obtain from the ADA if possible a list of school counselors in the area.
b. Determine which counselors are knowledgeable about education and work issues specific to persons with chronic diseases like diabetes.
c. Make a list of qualified school counselors to whom patients can be referred to keep on file.

Step 2. Refer adolescents with chronic diseases like diabetes to a vocational assessment center as part of career/vocational guidance.

a. Develop a list of regional assessment centers in your state.

b. Identify the centers or local education agencies who receive funding through the Carl D. Perkins Vocational Education Act of 1984 as these centers/agencies must serve students who are handicapped, educationally or economically disadvantaged, and/or who have limited English proficiency.
c. Know the services available through centers and agencies who receive vocational funds, e.g., vocational interest and aptitude assessment and special services like tutoring, counseling, and equipment modification.

Step 3. Offer or refer adolescent patients and family to courses/speakers that address employability issues.

a. Cover hiring practice topics: What employer biases about diabetes might the adolescent need to dispel in the interview and how can he/she do this.
b. Cover insurance/employment topics: How does company size and insurance factors affect a company's employment practices?
c. Cover occupational/career topics: What jobs have restrictions that prevent a person with diabetes from being hired.

G-4. **Promote age-appropriate financial responsibility.**

Performance Objective: At the end of this training module, the case management team member will be able to outline the financial considerations and responsibilities for purchasing disease-related items.

Primary Responsibility: Social Worker

Step 1. Involve adolescent patients in the purchase of supplies and equipment, teaching them how to shop for specials, select drug stores that provide good service, and so forth.

Step 2. Encourage patients and families to discuss and regulate budget for supplies and equipment and other diabetes related expenses.

G-5. **Promote linkage of patient/family with social service agencies.**

Performance Objective: At the end of this training module, the case management team member will be able to list community and county services, the contact persons at each service, and the conditions under which interaction with those persons/services is warranted.

Primary Responsibility: Social Worker

Step 1. Link patient to educational services to which by age they are entitled by law.

Step 2. Report cases of neglect and abuse to Children and Youth Services, Child Protective Services, which is county directed.

Step 3. Work through Juvenile Detention Services if youth with diabetes is being retained for criminal activity, or through the parole officer if the youth is not being detained.

Step 4. Work in conjunction with mental retardation/mental health centers.

Step 5. Work with private counselors or rehabilitation centers on a consultant type of arrangement.

Step 6. Contact Public Health Services and/or visiting nurses for support or medical care.

Step 7. Involve other pediatric/medical treatment personnel as appropriate.

Step 8. Link patient and family with other services like the Office of Vocational Rehabilitation, Social Security Insurance, and so forth.

H. FOSTER COMMUNITY AWARENESS

H-1. **Support and develop community services.**

Performance Objective: At the end of this training module, the case management team member will be able to prepare a resource guide of support agencies in the local region, describe a plan for assuring communication and interaction with the agencies, and identify other agencies/services needed but not available in the community.

Primary Responsibility: Social Worker, Nurse, Physician

Step 1. Identify the agencies/services available in your community.

a. List hospitals, physicians (office and corporation), pharmacy, home health services, public health services, school nursing services, community health clinics, student health services, and so forth.
b. List disease specific organizations and the state/local chapters and affiliates that deal with diabetes and related complications, e.g., American Diabetes Association, Juvenile Diabetes Foundation, National Society to Prevent Blindness, etc.
c. List other organizations such as eye clinics, vision centers, community mental health centers, vocational centers, rehabilitation centers, and general interest groups.

Step 2. Record the address, phone number, contact person, and service provided by each agency.

a. Use a separate page and a standard format for recording each agency's information.
b. Incorporate into the format specific information about the service provided, e.g., service goals, service area, hours of business, service costs, residence requirements, age requirements, and specific disabilities served.

Step 3. Identify specific purpose of interactions with each agency/service and mutual benefits of the interaction.

Step 4. Establish communication and a system for regular interaction.

Step 5. Make recommendations to professionals and family.

Step 6. Assess community needs for services not provided.

Step 7. Identify resources needed to develop new services.

H-2. **Participate in continuing education seminars.**

Performance Objective: At the end of this training module, the case management team member will be able to identify at least three disease-related topics of interest to other health professionals and three of interest to the general community, and state goals for addressing these topics in continuing education seminars.

Primary Responsibility: Physician, Nurse, Social Worker, Dietitian

Step 1. Make the health professional community aware of the diabetes team as a resource.

Step 2. Make other professionals in the community (school and company nurses, counselors, etc.) aware of the diabetes team as a resource.

Step 3. Establish a standard for minimum involvement of each team member in offering continuing education services.

H-3. **Promote media coverage.**

Performance Objective: At the end of this training module, the case management team member will be able to develop a promotion plan to assure community awareness of services and programs for adolescents with chronic diseases.

Primary Responsibility: Physician, Nurse, Social Worker

Step 1. Encourage local diabetes-affiliate organizations to get media coverage for their events

Step 2. Assure that all education programs receive promotion.

Step 3. Select appropriate types of media coverage for given events, e.g., local newspapers, hospital/institution newsletters, radio stations, television.

H-4. **Participate in community education programs.**

Performance Objective: At the end of this training module, the case management team member will be able to list at least 4 opportunities for volunteering or obtaining volunteers to speak to community groups.

Primary Responsibility: Nurse, Physician, Social Worker

Step 1. Inform speaker's bureau and groups interested in diabetes of the diabetes care team as resources for their programs.

Step 2. Volunteer to speak to community organizations like Kiwannis Club or Rotary Club and to professional organizations like the American Marketing Association regarding factors involved in hiring part-time or full-time adolescent workers. (Educate to eliminate misconceptions.)

Step 3. Make the community aware of the diabetes team as a resource for health awareness. (For example, businesses could benefit by providing health education as part of an employee assistance program, educating employees about their roles in case management of any chronic disease with the goal of reducing employee sick days and insurance costs.

Step 4. Get well-known people, like sports figures, to serve as guest speakers in a school assembly as part of a health week program if possible.

Step 5. Ask patients who have made particular strides in care and who have had unusual and uplifting experiences though having diabetes to speak to appropriate youth groups.

a. Have the patients speak about their accomplishment and how they managed their diabetes under unusual circumstances.
b. Have patients speak about their transitions to college, e.g., how they managed the changing lifestyle and their diabetes at the same time.

H-5. Disseminate information about the need for and availability of services to target population.

Performance Objective: At the end of this training module, the case management team member will be able to prepare a pamphlet or folder that conveys the nature and scope of services available to adolescents with chronic disease and their families.

Primary Responsibility: Nurse, Social Worker, Physician

Step 1. Convey optimal care standards adopted by the case management team and service providers (clinics, hospitals, public health agencies).

Step 2. Detail specific components of diabetes case management programs. (See the presentation in the COMPETENCY PROFILE.)

I. MAINTAIN PROFESSIONAL COMPETENCY AND AWARENESS

I-1. Discuss professional issues with peers.

Performance Objective: At the end of this training module, the case management team member will be able to list at least 3 specific meetings/sessions at which to discuss professional issues with peers.

Primary Responsibility: Physician, Nurse, Dietitian, Psychologist, Social Worker, Exercise Physiologist

Step 1. Participate in appropriate local, national, and professional organizations, including, but not limited to, the American Diabetes Association, Juvenile Diabetes Foundation and the American Association of Diabetes Educators.

Step 2. Obtain professional observations, analyses, and recommendations from other team members regarding patient's care and treatment.

Step 3. Meet with specialists on the support team to discuss treatment.

I-2. Participate in regular inservice programs.

Performance Objective: At the end of this training module, the case management team member will be able to describe benefits of various in-service programs.

Primary Responsibility: Physician, Nurse, Dietitian, Psychologist, Social Worker

Step 1. Attend training sessions offered by sales representatives of various drug and equipment suppliers.

Step 2. Attend education and training sessions offered by the employer (institution/clinic).

I-3. Read professional journals.

Performance Objective: At the end of this training module, the case management team member will be able to list at least 3 journals to read monthly and schedule time to read them.

Primary Responsibility: Physician, Nurse, Dietitian, Psychologist, Social Worker, Exercise Physiologist

Step 1. Obtain subscriptions to disease-specific journals, e.g., Diabetes Care, Pediatric and Adolescent Endocrinology, Diabetes, Diabetic Medicine, The Diabetes Educator.

Step 2. Read other relevant journals, e.g., Journal of Adolescent Health Care, Developmental Medicine and Child Neurology, Journal of Pediatrics, Journal of Chronic Diseases, Pediatric Nursing.

Step 3. Set aside time to read about current trends, issues, research.

I-4. Attend professional seminars and conventions.

Performance Objective: At the end of this training module, the case management team member will be able to identify the dates of various professional seminars and conferences for the year and check those that it is possible to attend.

Primary Responsibility: Physician, Nurse, Dietitian, Psychologist, Social Worker, Exercise Physiologist

Step 1. Attend at least one of the following events annually.

American Diabetes Association Professional Meeting
American Diabetes Association Post-Graduate Course
American Association of Diabetes Educators

Step 2. Attend other professional meetings as desired. Examples include: International Diabetes Federation, International Study Group for Diabetes in Children, American Dietetics Association, American Psychological Association, Society for Adolescent Medicine, et. al.

Step 3. Attend and participate in diabetes camp programs.

I-5. Obtain licensure and maintain certification for the individual.

Performance Objective: At the end of this training module, the case management team member will be able to identify the status of licensure and certification of team members and goals for acquiring further certification.

Primary Responsibility: Physician, Nurse, Dietitian, Psychologist, Social Worker, Exercise Physiologist

Step 1. Physicians should achieve board certification in pediatrics or internal medicine and sub-specialty certification in endocrinology or adolescent medicine.

Step 2. Educators, dietitians and mental health professionals should achieve Certified Diabetes Educator (CDE) status under the auspices of the American Association of Diabetes Educators.

Step 3. Team members credentials should reflect other appropriate certifications including, but not limited to, nurse practitioners, registered dietitians, ACSW, clinical psychology.

Step 4. Recertify as appropriate.

J. KEEP OFFICE/CLINIC RECORDS

J-1. Obtain graphs and plot blood pressure, height and weight.

Performance Objective: At the end of this training module, the case management team member will be able to obtain or develop and use graphs to plot blood pressure, height, and weight.

Primary Responsibility: Nurse, Physician

Step 1. Get height, weight, and velocity charts (Ross vs. Genentech).

Step 2. Get BP% charts (Wyeth).

Step 3. Teach staff how to use the charts.

Step 4. Teach patients how to use appropriate graphs, charts, e.g. , glucose graph.

Step 5. Have patients bring their graphs or charts to their appointment and file a copy with other charts.

Step 6. Teach staff how to spot inconsistencies, errors.

Step 7. Establish Tx protocol for abnormalities.

J-2. Set up/maintain flow sheets.

Performance Objectives: At the end of this training module, the case management team member will be able to set up flow charts with guidelines for data entry and review.

Primary Responsibility: Nurse, Physician, Dietitian

Step 1. Identify important longitudinal variables.

Step 2. Set up flow sheet (see example).

Step 3. Identify team member responsible for data entry.

Step 4. Establish protocol for flagging absolute values and Tx protocol to ameliorate.

J-3. **Set up/maintain up-to-date problems list.**

Performance Objective: At the end of this training module, the case management team member will be able to describe a system for keeping up-to-date problem information readily available.

Primary Responsibility: Nurse, Physician, Dietitian

Step 1. Establish front/top sheet format for patient identification, phone, insurance, referral doctor/source.

Step 2. Establish format for problem list.

Step 3. Set up chart so it is always seen before each patient contact.

J-4. **Maintain medical, educational, and psycho-social status.**

Performance Objective: At the end of this training module, the case management team member will be able to describe a process for assessing minimum care standards provided by the diabetes team/institution.

Primary Responsibility: Nurse, Physician, Dietitian, Psychologist, Social Worker

Step 1. See Council on Diabetes and Youth (CODY) minimum care guidelines.

Step 2. Refer to classification guidelines, such as those noted in "Classification and Diagnosis of Diabetes Mellitus in Children and Adolescents" by Arlan Rosenbloom, et al., Journal of Pediatrics, 1981; 98-320-323.

Step 3. Use log book pages and follow up sheets to record information on a regular basis. (See Appendix of Pediatric and Adolescent Diabetes Mellitus by Stuart J. Brink.)

J-5. **Collate records from team and consultants.**

Performance Objective: At the end of this training module, the case management team member will be able to prepare checklists for patient care and treatment and file these and other records in an orderly, efficient manner.

Primary Responsibility: Nurse, Physician

Step 1. Set up chart format, i.e., most current entry on top, etc.

Step 2. Establish a re-educational checklist regarding the following:

a. Hypoglycemia, yearly in Spring
b. Sick day guidance, yearly in Fall
c. Monitoring techniques, every 6-12 months
d. Insulin adjustment guidelines, every 6 months

Step 3. Establish mandatory consultation checklist.

a. Nutrition at least 1-2 times a year
b. Psychosocial at least once a year
c. Ophthalmologist at year 5 and yearly thereafter

Step 4. Establish mandatory lab checklist regarding the following and with times not exceeding the intervals noted in ADA standards:

a. GHb, every 2-4 months
b. Lipids, yearly or every 6-12 months
c. Renal function yearly or after puberty
d. Thyroid function every 6-12 months

Step 5. Set up a system for communication: How will consultant letters be seen by all team members? Who will communicate with home doctor? with patient and family?

J-6. **Ensure adequacy of records for providing rapid review of patient history and status.**

Performance Objective: At the end of this training module, the case management team member will be able to describe the process for developing, evaluating, and producing record forms that provide rapid and clear review of patient history and status.

Primary Responsibility: Nurse, Physician, Dietitian, Social Worker

Step 1. Develop, adapt, or adopt materials to use in a record file or book.

Step 2. Ask teams members to review the utility and comprehensiveness of the forms (charts, graphs, log book pages, records, etc.).

Step 3. Prepare forms for pilot test by team members.

Step 4. Revise forms in keeping with pilot test results

Step 5. Field test forms for utility and comprehensiveness by involving other sites in use of the materials.

Step 6. Obtain input from field test use and review.

Step 7. Revise and produce final forms based on field test results.

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COMPETENCY PROFILE OF CASE MANAGEMENT FOR THE ADOLESCENT/YOUNG ADULT WITH CHRONIC DISEASE

Developed through
DACUM Workshop
February 28-March 1, 1989

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Bureau of Maternal and Child Health

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Case Management for the Adolescent/Young Adult with Chronic Disease

Provides medical, educational, and psychosocial support programs to help adolescents achieve optimal health and successful transitions to adult care.

Duties					
A **Establish & Maintain Contact**	A-1 Identify target population	A-2 Teach patients about the benefits of health supervision	A-3 Teach patients/families how to use the team	A-4 Help patient/family deal with financial barriers	A-5 Establish follow up metho
B **Provide an Individualized Health Care Team**	B-1 Assure institutional recognition	B-2 Assure competency of team members	B-3 Assess patient & family needs for professional assistance	B-4 Identify the health care team responsible for patient case management	
	B-10 Anticipate & plan transition to adult health care team				
C **Provide Disease Management Education & Promote Responsible Self-Care**	C-1 Assess knowledge, skills, attitudes & beliefs	C-2 Ensure learning of basic disease management skills		C-3 Assess learning capabilities & styles	C-4 Teach adv for flexible dise stresors, & safe
	C-8 Teach about the long-term consequences of the chronic disease	C-9 Teach the art of negotiating for self-management & responsibility	C-10 Teach about the adult care system	C-11 Provide genetic counseling	C-12 Provide p conception med & psychological counseling
D **Improve Patient's Health Status**	D-1 Evaluate & improve metabolic control	D-2 Encourage optimal emotional growth	D-3 Assess physical growth & development	D-4 Promote physical fitness	D-5 Promote healthy dietary practices
E **Assure Appropriateness of Patient Equipment**	E-1 Assess patient's particular supply & equipment needs	E-2 Identify sources of supplies & equipment	E-3 Ensure that equipment works	E-4 Periodically reassess patient's equipment needs	
F **Provide Psychological Support**	F-1 Assess school performance & cognitive, social, & emotional status of patient & family	F-2 Promote positive self-image & patient optimism to master the requirements of diabetes & to achieve victorious living (life goals)		F-3 Promote appropriate social support networks	
	F-9 Follow up on recommendations & referrals	F-10 Assure adequate on-going communication among all team members in chronic situations		F-11 Provide prospective psychosocial assessment & preventive counseling in new onset & high risk families	
G **Address Economic & Social Needs**	G-1 Assess economic & social service needs & link to resources	G-2 Plan for adult health care coverage	G-3 Provide for vocational advice & career counseling	G-4 Promote age-appropriate financial responsibility	G-5 Promote linkage of patie family with soci service agencie
H **Foster Community Awareness**	H-1 Support & develop community services	H-2 Participate in continuing education seminars	H-3 Promote media coverage	H-4 Participate in community education programs	H-5 Dissemin the need for & to target popul

Tasks

ds	A-6 Address barriers to contact				
	B-5 Identify the support team	B-6 Coordinate the team	B-7 Coordinate the patient's case management plan	B-8 Facilitate active involvement of patient & family	B-9 Reassess patient & family needs for professional assistance

anced self-care skills ase management, weight control	C-5 Teach creative meal planning for a flexible lifestyle	C-6 Teach interaction of adolescent body changes, behaviors, & psycho-social status with the chronic disease	C-7 Expose patient to instructional materials that help them to minimize the consequences of potentially dangerous adolescent behaviors

re- ical	C-13 Periodically reassess & reeducate as necessary	C-14 Transfer to adult health care system		
	D-6 Evaluate for disease related complications	D-7 Treat chronic disease complications	D-8 Address risk factors of tobacco, alcohol, drug abuse, & sexual activity	

	F-4 Identify and address psychosocial causes of poor control	F-5 Ensure mental health interventions in cases of recurrent medical crises	F-6 Identify psycho-pathology including depression, eating disorders, separation anxiety, psychosis, suicide, school absenteeism, work absenteeism, & refer for treatment	F-7 Provide crisis counseling when needed	F-8 Negotiate changing family roles
nt/ al s					
ate information about availability of services ation					

(I and J continued on back)

Duties	Tasks				
I Maintain Professional Competency & Awareness	I-1 Discuss professional issues with peers	I-2 Participate in regular inservice programs	I-3 Read professional journals	I-4 Attend professional seminars & conventions	I-5 Obtain licensure & maintain certification for the individual
J Keep Office/Clinic Records	J-1 Obtain graphs & plot blood pressure, height & weight	J-2 Set up/ maintain flow sheets	J-3 Set up/ maintain up-to-date problems list	J-4 Maintain medical, educational, & psychosocial status	J-5 Collate records from team & consultants
	J-6 Ensure adequacy of records for providing rapid review of patient history & status				

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